

Madison County, New York
HEALTH PROFILE:

Lyme
Disease

2018

Madison County
Health Department



A person's risk of being bitten by a tick exists year-round, but remains the greatest between May and October.



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LYME DISEASE AND TICKS

Background

Lyme disease was first described at the end of the 1970's following an investigation of a cluster of arthritis cases among children living near Lyme, Connecticut. In 1982, it was identified that Lyme disease is spread by the bacteria known as *Borrelia burgdorferi*.

Lyme disease is the most common illness spread by the blacklegged tick, (*Ixodes scapularis* or commonly referred to as a deer tick). Other serious but less common diseases can also spread through the bite of an infected tick, such as anaplasmosis (blacklegged tick), ehrlichiosis (lone star tick), babesiosis (blacklegged tick), and Powassan virus (blacklegged tick).

Lyme disease became reportable in New York State (NYS) in 1986. In 1990, Lyme disease became a nationally notifiable disease. Cases of Lyme Disease are reported based on the county

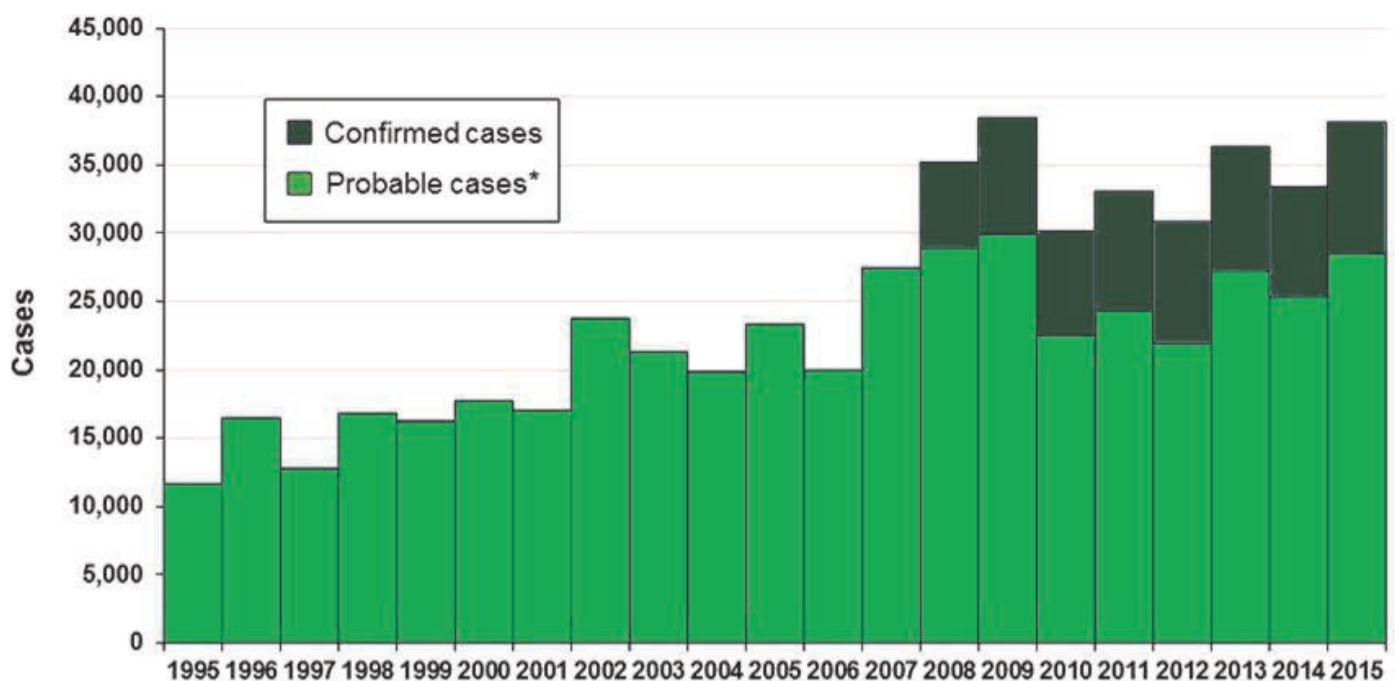
of residence and may not reflect the location where a person was infected with Lyme disease.

In 1998, the Food and Drug Administration (FDA) approved a Lyme disease vaccine for persons 15-70 years of age, however in 2002, the vaccine was withdrawn by the manufacturer, citing insufficient consumer demand. Protection with the vaccine diminished over time and anyone who received the vaccine prior to 2002 is probably no longer protected by the vaccine. No vaccine for Lyme disease has been available since.

Lyme disease is the most common vector-borne disease in the United States and in 2015 was reported the sixth most reported notifiable disease nationally (CDC, 2016e). Lyme disease represents a major challenge to the public health and medical communities.

A study examining laboratory testing data from

Figure 1:
Reported Cases of Lyme Disease by Year, United States, 1995-2015 (CDC 2016b)



*National Surveillance case definition revised in 2008 to include probable cases.

Table 1:
Human Cases and Incidence Rates (per 100,000) of Lyme Disease (NYSDOH, email communication)

County	2013		2014		2015		2016	
	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate
Chenango	34	68.1	37	74.7	63	127.5	44	90.6
Cortland	8	16.2	14	28.6	11	22.4	25	52
Herkimer	38	58.9	20	31.2	35	54.9	25	39.9
Madison	35	48.4	7	9.7	17	23.5	29	40.7
Oneida*	82	35.1	41	17.6	89	38.2	33	14.3
Onondaga*	98	21	130	27.8	127	27.1	11	2.4
Oswego	56	46	35	28.9	51	42.2	76	63.9
Otsego*	63	102.1	53	85.9	101	165.2	106	176.4

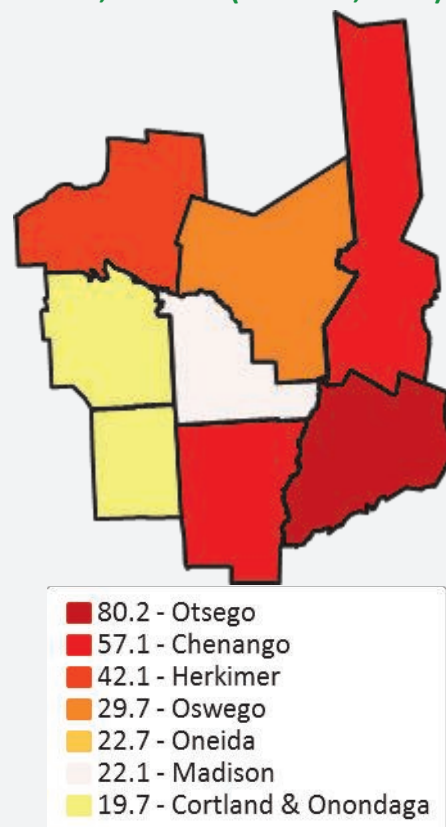
*Counties participating in Lyme disease surveillance using sampling estimation. Listed cases and rates are extrapolated. Data Source: NYSDOH

2008, estimated that 288,000 (range of 240,000-400,000) new Lyme disease cases occur each year in the United States (Hinckley, 2014). The number of cases of Lyme disease has increased over the last 14 years (Figure 1). In 2015, the national rate of Lyme cases was 11.32 per 100,000 population. Of the confirmed Lyme disease cases in 2015, ninety-five percent (95%) were reported from just fourteen states, including New York (CDC, 2016e).

New York is considered a high risk, endemic Lyme disease state. From 2006-2016, more than 35,000 cases of Lyme disease were reported by New York State for an incidence rate of 13.3 per 100,000 population (CDC, 2016c).

In Madison County, between 2014-2016, the incidence rate was 22.1 cases per 100,000 population (Figure 2). Madison County reported its highest incidence of Lyme disease, 48.4 cases per 100,000 population in 2013 (Table 1). Five of seven counties contiguous to Madison County, reported higher incidence rates of Lyme disease

Figure 2:
Lyme Disease Incidence Rate
per 100,000 Population by County in New
York, 2012-14 (NYSDOH, 2016)



from 2014-16 (NYSDOH, 2016). The highest incidence reported by a contiguous county was Otsego, reporting 176.4 per 100,000 in 2016 (NYSDOH, email communication).

Local and statewide incidence rates of Lyme disease however are likely much higher, as with many other reportable diseases, Lyme disease cases are under reported (White et al, 2016 and Nelson et al, 2015). Not all people who develop Lyme disease seek healthcare and reporting of symptomatic cases by medical providers is not adequate, and contribute to underreporting.

Reviewing reported cases, the greatest risk for infection is known to occur when a tick is in the immature (or nymphal) stage, coinciding when the most cases of Lyme disease are reported. Thus the life cycle of the tick plays an important role in the spread of Lyme disease.

Tick Life Cycle

Knowing the complex life cycle of the tick can help in understanding the risk of getting the disease and how to prevent it.

Ticks search for host animals from the leaf litter on the forest floor or from the tips of grasses and shrubs. Ticks crawl onto animals or people as they brush against them. Ticks obtain blood by inserting their mouth parts into the skin of a person or animal. Blacklegged ticks are slow feeders: one meal can take several days. As they feed, their bodies slowly enlarge. The degree of body engorgement reflects the time the tick was attached.

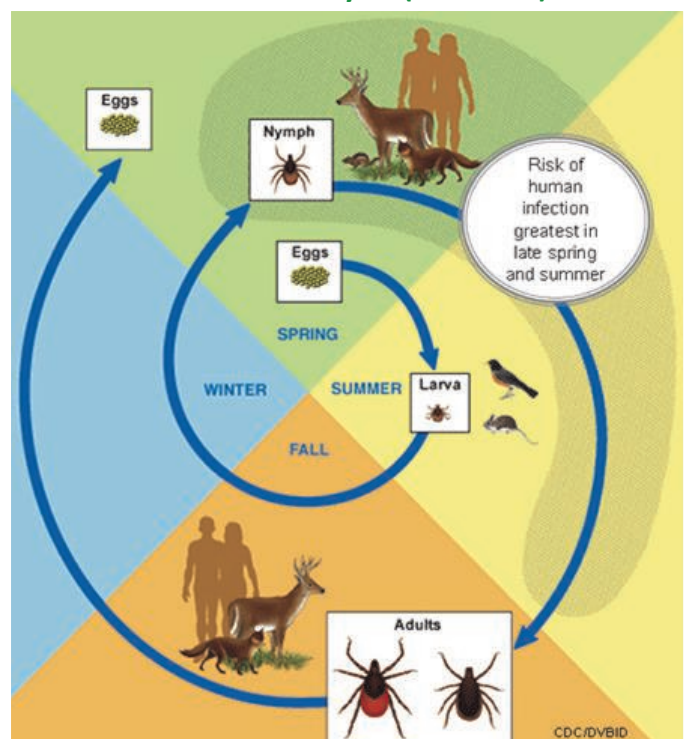
The tick goes through four life stages (egg, larva, nymph, and adult) before completing its 2-year life cycle. Tick eggs are laid in the spring, and hatch as larvae in the summer. Larvae feed on mice, birds, and other small animals in the

summer and early fall. The larvae may become infected with Lyme disease bacteria when feeding on these animals. Once a tick becomes infected, it stays infected for the rest of its life and can transmit the bacteria to other host animals.

After its initial feeding, the larvae usually become inactive (or dormant) until the following spring, when they change into immature ticks, called nymphs.

Nymphs feed on small rodents, birds, and other small mammals in late spring and early summer. Nymphs will also feed on humans, and if previously infected with Lyme disease bacteria, they can transmit the disease to humans. Nymphs molt into adult ticks in the fall, peaking in October through November. In the fall and early spring, adult ticks feed and mate on large animals, such as deer. Adult ticks are most active during the cooler months of the year but when

Figure 3:
Deer Tick Life Cycle (CDC 2015)



temperatures are above freezing. Adult female ticks will sometimes also feed on humans. In spring, adult female ticks lay their eggs on the ground, completing their life cycle (Figure 3).

Most cases of Lyme disease are reported from May through August, corresponding to the peak spring and summer activity period for nymphs (Figure 3) and for people (Figure 4). This suggests that the majority of Lyme disease cases are transmitted at the nymphal life stage (Clover and Lane, 1995 & Stafford, 2007). Unlike larger adult ticks, nymphs are difficult to see due to their small size (less than 2mm), and are less likely to be detected and removed before they spread Lyme disease (Stafford).

Disease Transmission

Not every tick is infected with the bacteria that causes Lyme disease. The potential for contracting Lyme disease in an area depends on these key factors (Pepin et al., 2012):

1. Tick species able to transmit the bacteria causing Lyme in adequate abundance or density
2. Prevalence of *B. burgdorferi* infection in ticks
3. Contact frequency between infected ticks and people

Figure 4:
Confirmed Lyme Disease Cases by Month of Disease Onset—United States, 2001-2015 (CDC 2016b)

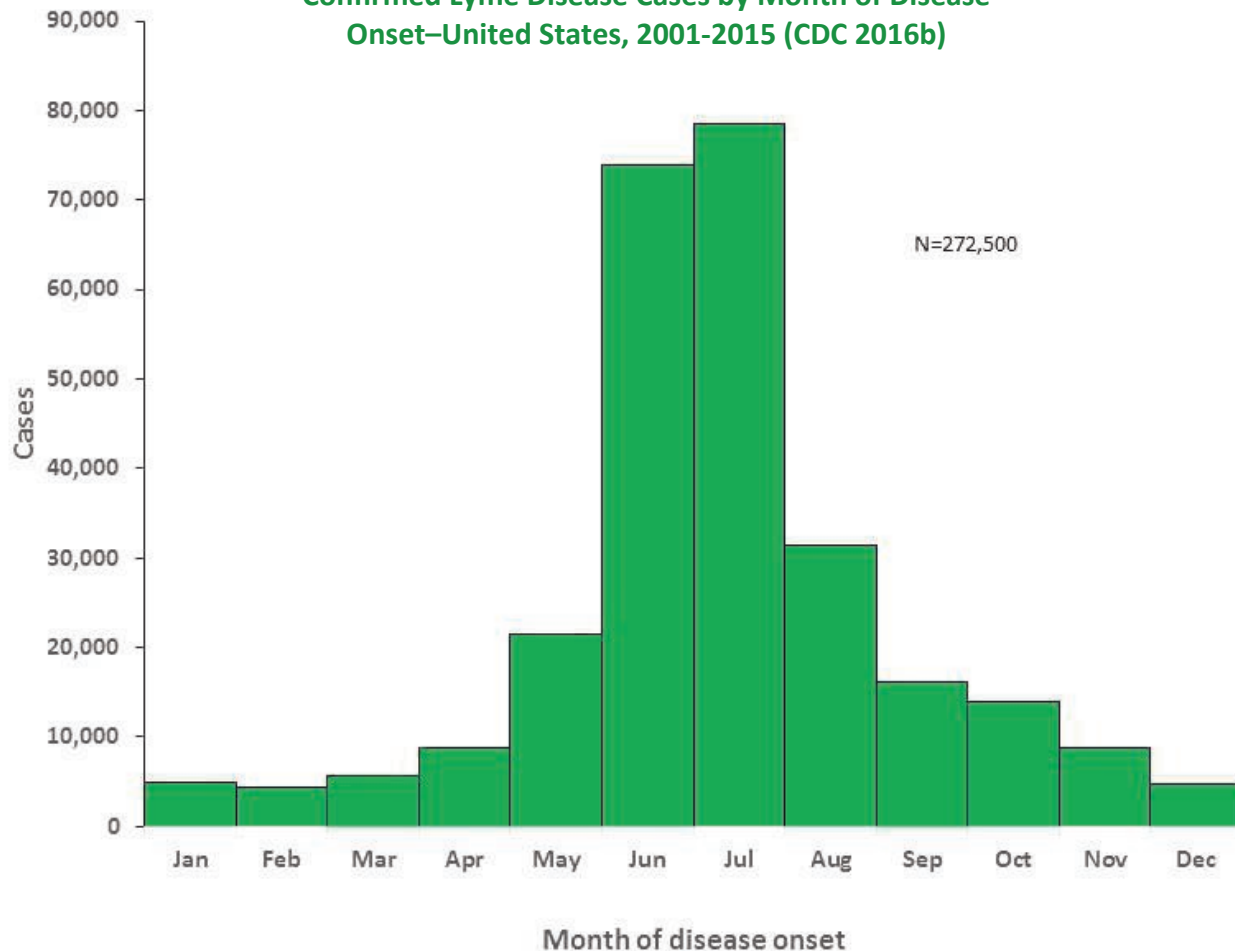




Photo of an engorged tick that has fed for over 24 hours.

According to the CDC, a tick must be infected with the Lyme-disease causing bacteria and be attached for at least 24 hours before Lyme disease can be passed to a person from the bite of an infected tick (CDC, 2017d).

A person's risk of being bitten by a tick exists year-round, but remains the greatest between May and October (Figure 4). Ticks may be out searching for a host any time winter temperatures are above 40° F and when the ground is not frozen or covered with snow. Ticks also need constant, high relative humidity at ground level.

Ticks can attach to any part of the human body but are often found in hard-to-see areas such as the groin, armpits, and scalp.

Similar to other bacterial infections, previous Lyme disease infection does not provide immunity in the future. A person may be re-infected with Lyme disease again if bitten by another infected tick (NYSDOH, 2017).

Additionally, according to the CDC (CDC, 2015):

- There is no evidence that Lyme disease is transmitted from person-to-person.
- There is no credible evidence that Lyme disease is transmitted through air, food, or water.
- There are also no reports of Lyme disease transmission from breast milk.
- A mother infected with Lyme disease during pregnancy may lead to infection of the placenta and possible stillbirth; however, no negative effects to a fetus have been found when the mother receives appropriate treatment.
- No cases of Lyme disease have been linked

to blood transfusions, but scientists have found that the Lyme disease bacteria can live in blood stored for donation.

- There is no evidence that cats and dogs can spread Lyme disease directly to their owners. However, pets can give infected ticks a ride into a person's yard and home.
- Lyme disease can not be spread to a person from eating venison or squirrel meat, but hunting and dressing deer or squirrels may bring a person into close contact with infected ticks.

At-Risk Populations

People who spend time outdoors in activities such as camping, hiking, golfing, working, gardening, or playing in grassy, brushy, and wooded environments are at increased risk of coming into contact with a tick infected with Lyme disease. However, ticks can also be carried by animals onto lawns and gardens and into houses by pets.

The incidence and prevalence of the disease from occupational exposure has not been precisely defined. Several studies, however, have identified outdoor occupational exposure as a risk factor (Magri et al, 2002 and Piacentino et al., 2002). The true incidence of occupationally acquired Lyme disease is hard to define because pinpointing the exact circumstances of infection is exceedingly difficult (OSHA, n.d.). In fact, the majority of infected persons do not recall being bitten by a tick.

Lyme disease can affect people of any age, however CDC data from 1992-2006 show that the average annual incidence of Lyme disease is highest among children aged 5-9 years (8.6 cases

Figure 5:
Confirmed Lyme Disease Cases by Age and Sex--United States, 2001-2015 (CDC, 2016b)

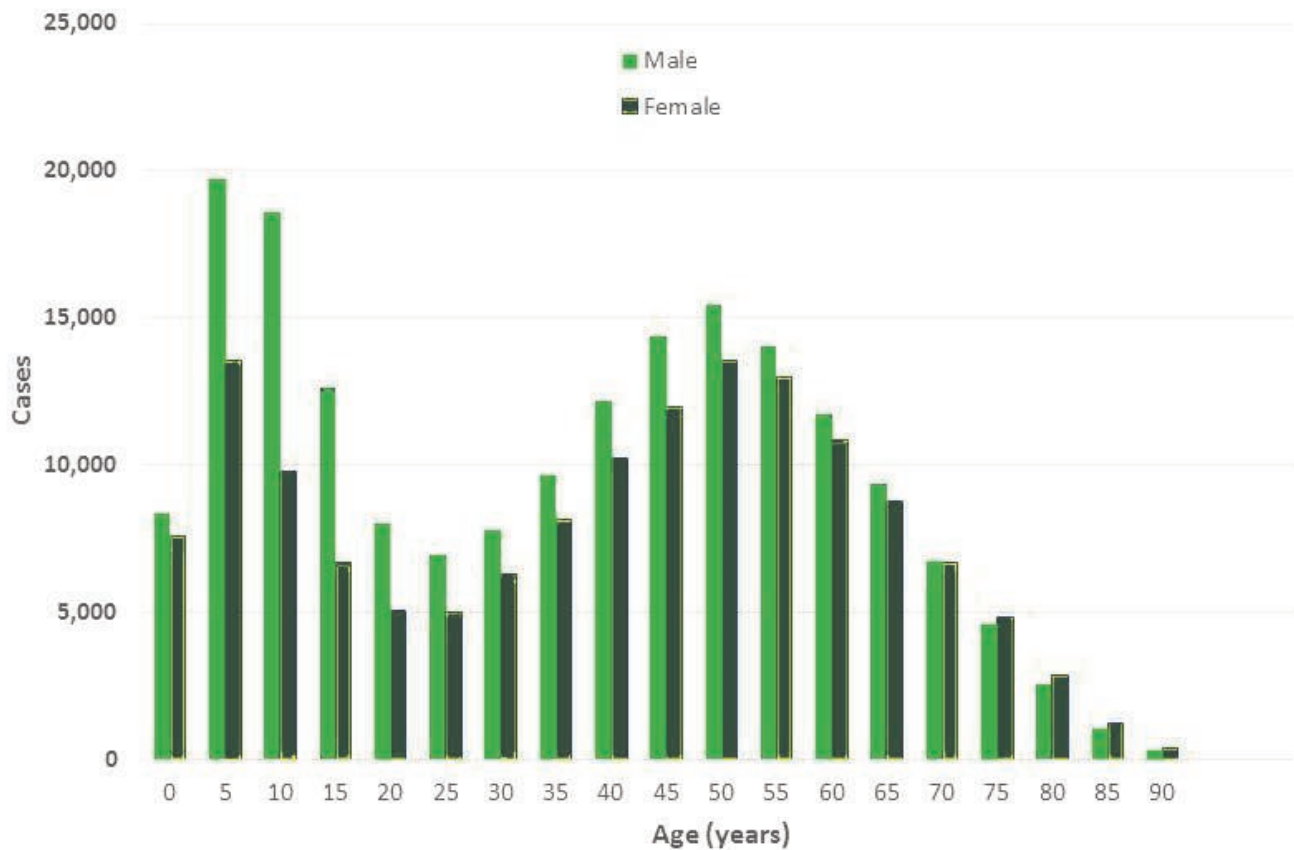
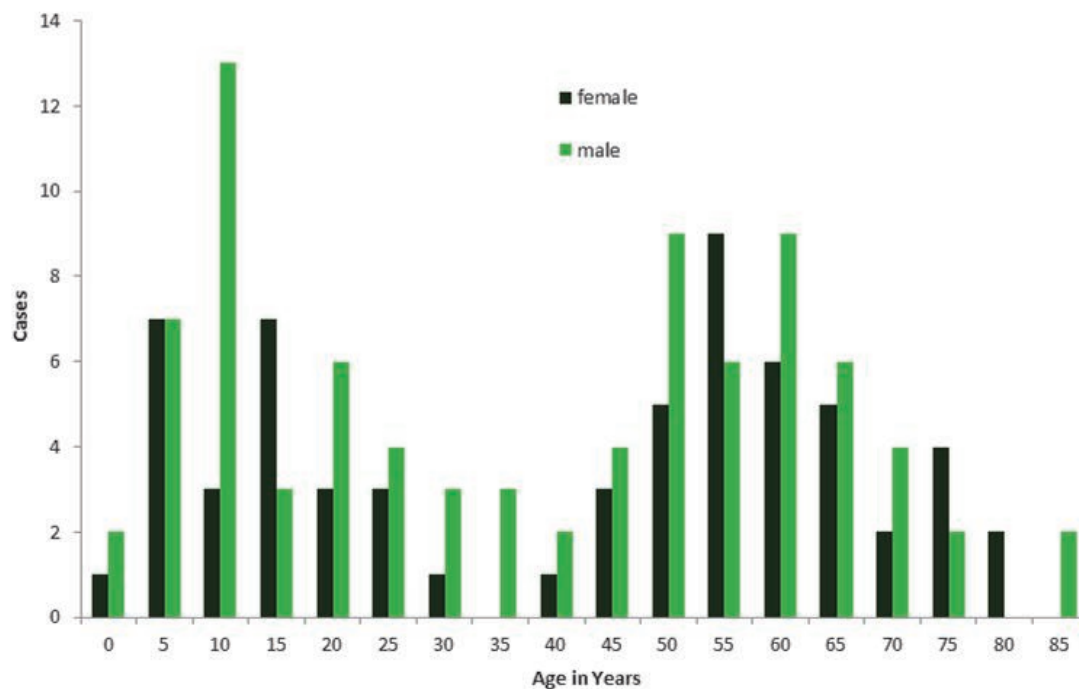


Figure 6:
Confirmed and Probable Lyme Disease Cases by Age and Sex--Madison County, 2011-2017*



per 100,000 population) and adults aged 55-59 years (7.8 cases per 100,000 population) (Figure 5). The lowest rate was reported among adults aged 20-24 years (3 cases per 100,000 population) (Figure 6). Overall rates for males remains higher across all ages groups. Rates among young males, ages 5-9 increased disproportionately compared with young females; the cause for this difference is unknown (CDC, 2008).

Examining Lyme disease cases in Madison County from 2011-17, 57.8% (85 cases) have been among males (Table 2). Lyme disease in Madison County follows the national trend of disproportionately higher disease rates in males and within specific age groups (5-9 and 55-59).

A 2017 study by Jones et al. found pet-owning households of cats or dogs had 1.83 times the risk of encountering ticks and 1.49 times the risk of finding ticks attached to household members compared to households without pets. This study among residents in three Lyme disease-endemic states (Connecticut, Maryland, and New York State), suggests that pet owners may be at increased risk of developing tick-borne disease. This may be especially important for pet owners who allow their pets to share their indoor living space and furniture, however more research is needed to better understand the risk for disease among households with pets.

Specific risk factors for exposure to blacklegged (deer) ticks have not been fully described (Jones et al, 2017). Exposure to tick bites alone does not explain the differences in rates of Lyme disease by sex and age.

More studies are needed to identify sociological, behavioral, biologic, or immunologic reasons for the differences in rates of Lyme disease by age and sex. Understanding the reasons for differences in Lyme disease rates is key to improving prevention programs targeting populations at greatest risk for Lyme disease.

Table 2:
Percent of Lyme Disease by Sex—
Madison County, 2011-2017*

Male	Female
85 cases	62 cases
57.8%	42.2%

*Includes confirmed and probable cases; 2017 data including through 8/23/17.

Signs and Symptoms

The risk of Lyme disease infection from a tick bite depends on several factors, including whether the type of tick is a blacklegged tick, if the tick was encountered in a geographic area where Lyme disease is common, and if the tick was infected and attached long enough to transmit Lyme disease.

A tick bite may cause a skin reaction or irritation like a rash, but a reaction or irritation to a bite is not a sign of Lyme disease infection. Skin irritations from a tick bite are typically less than 2 inches (5 cm) in largest diameter, develop within 1-2 days after a tick is removed or detaches, and commonly disappear within 24-48 hours (Wormser, 2006).

Unlike a skin irritation, an erythema migrans (EM) rash is a common, distinctive sign of early Lyme disease infection. For the majority (70%–80%) of cases, the disease begins with a characteristic erythema migrans (EM) rash and accompanying flu-like symptoms (Steere et al, 1977). An erythema migrans rash typically appears within 3-30 days (7 days on average)

after a tick bite and commonly disappears within a month. The presence of an EM rash or lesion allows for a clinical diagnosis of Lyme disease infection to be made by a physician without laboratory confirmation when there is also a history of possible exposure to infected blacklegged ticks in the last 30 days (CDC, 2016d).

An EM rash may vary in appearance. The rash begins at the site of the tick bite as a red patch (macule) or raised lesion (papule), and may rapidly expand in size from at least 2 inches to 12 inches in diameter or greater (Aguero-Rosenfeld et al, 2005). It may form a solid red circle or it may develop central clearing. The rash may form one or multiple red rings, commonly called a "bull's-eye" rash (Figure 7). An EM rash also have a blue-purple hue, and crusted or blistering lesions have all been documented. The rash may be warm to the touch. In later stages of Lyme disease, rashes may appear on multiple areas of the body.

Early or localized Lyme disease infection may either be asymptomatic, or symptomatic with the following flu-like symptoms: fever, chills, headache, fatigue, muscle and joint aches, stiff neck, and swollen lymph nodes.

Figure 8 represents the breakdown of reported Lyme disease cases nationally from 2001 to 2015 by disease manifestation. The majority of cases experienced an erythema migrans rash (71%), followed by arthritis (30%) as clinical manifestations of Lyme disease infection (CDC 2016b). Other manifestations are less common and some people have more than one symptom presentation.

If Lyme disease is unrecognized or untreated in the early stage, more severe symptoms of late or disseminated stage Lyme disease infection may occur. As the disease progresses, severe fatigue, a stiff aching neck, and tingling or numbness in the arms and legs, or facial paralysis can occur. The most severe symptoms of Lyme disease may not appear until weeks, months or years after the tick bite. These can include severe headaches, painful arthritis, swelling of the joints, and heart and central nervous system problems (NYSDOH, 2017).

Figure 7:
Common Symptoms of Lyme Disease (CDC 2006d)

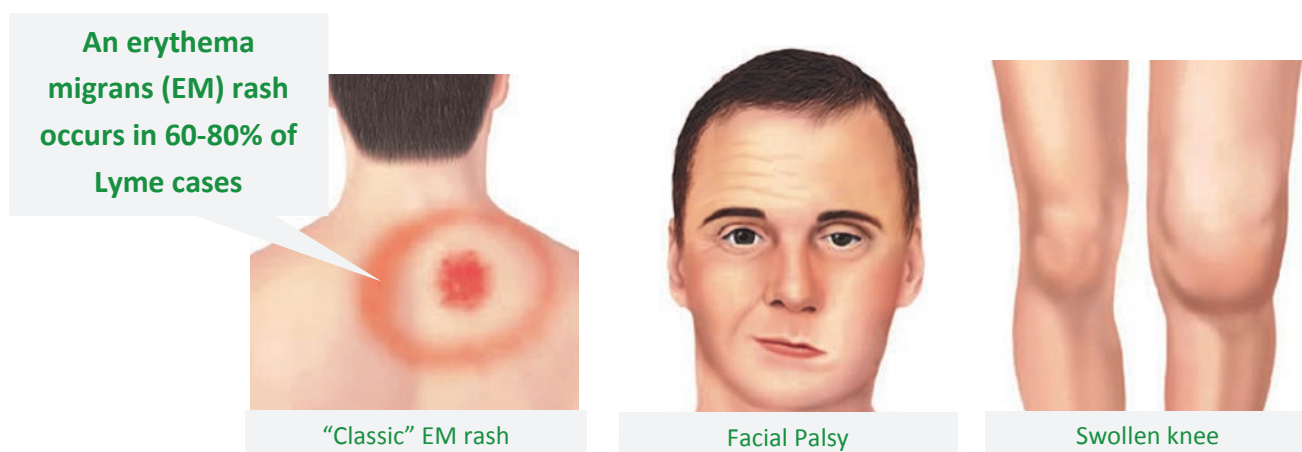
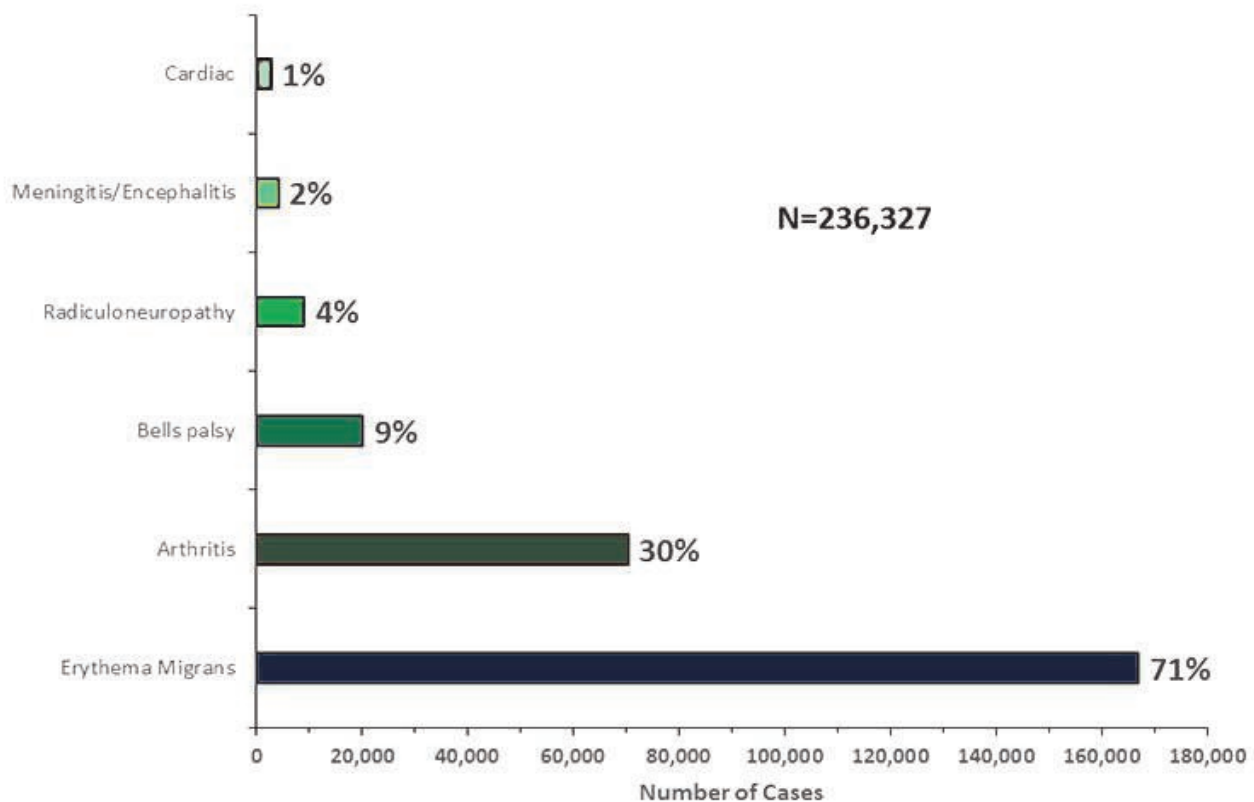


Figure 8:
Clinical Manifestations of Confirmed Lyme Disease Cases—United States, 2001-2015 (CDC 2016b)



Diagnosis and Testing

Lyme disease is diagnosed based on:

- Signs and symptoms
- A history of possible exposure to infected blacklegged ticks, and
- Laboratory testing

Patients with an erythema migrans (EM) lesion and epidemiologic risk (e.g. live in a high risk area) can receive a diagnosis without laboratory testing, and without a known tick bite. For all other patients, laboratory testing is needed to confirm the diagnosis, but proper interpretation depends on symptoms and timing of illness (Moore et. al, 2016)

In the absence of an erythema migrans (EM) rash to clinically diagnosis a case of Lyme disease, laboratory blood tests are helpful if used correctly and performed with validated methods. Lyme disease testing measures a person's antibody (or immune response) to the bacteria that cause Lyme disease. The accuracy of laboratory testing for Lyme disease depends upon the stage of disease.

During the first 2 to 3 weeks of infection, when a erythema migrans rash is likely to be present, a blood (serologic) test is expected to be negative (CDC, 2017d). Blood testing is more accurate and sensitive the longer someone has been infected, allowing time for the development of antibodies to be made and detected.

The CDC recommends a 2-tiered approach to Lyme disease blood serum (serologic) testing. If the results of the first test are positive or indeterminate, designated supplementary testing (Western blot) is performed to increase testing specificity. As with other serologic tests, the sensitivity and specificity of this 2-tiered approach vary by stage of disease. Two-tiered testing is relatively insensitive (<40%) during early illness, characterized by the presence of an EM rash. It is reasonably sensitive (>87%) and specific (99%) when used for diagnostic testing of late stage, disseminated Lyme disease (Aguero-Rosenfeld, 2005). For this reason, the CDC recommends this 2-tiered approach primarily for patients having signs and symptoms of late stage disease.

Examining 2008 testing data from seven participating commercial laboratories in four Lyme endemic states, Hinckley et al. 2014, found most Lyme disease testing was in accordance with current recommendations; at least 62% of tests conducted nationwide by laboratories participating in the study utilized the 2-tiered procedure recommended by the US Public Health Service agencies and the Infectious Diseases Society of America (Wormser 2006).

It is possible for someone who was infected with Lyme disease to test negative because (CDC 2017d):

- Some people who receive antibiotics early, within the first few weeks after a tick bite, may not develop antibodies or may only develop them at levels too low to be detected by the test.
- Antibodies against Lyme disease bacteria usually take a few weeks to develop. Tests performed early may be negative even if the person is infected. In this case, if the person is retested correctly a few weeks later, they should have a positive test if they have Lyme

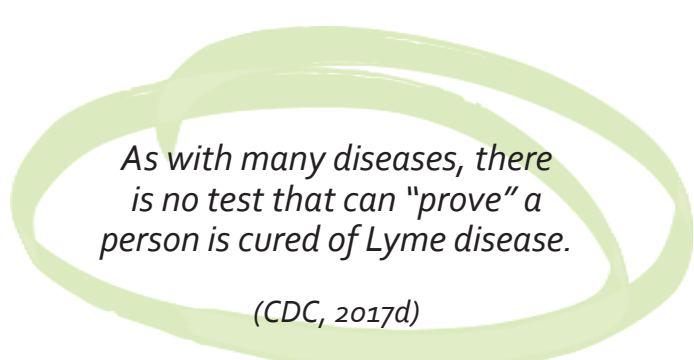
disease. It is not until 4 to 6 weeks after infection that a test is likely to be positive.

It is also important to note that Lyme disease testing can also provide false positive results by cross reacting to antibodies related to some viral infections and autoimmune diseases (CDC, 2017d).

Tests for Lyme disease detect antibodies produced by the human immune system to fight off the bacteria (*Borrelia burgdorferi*) that causes Lyme disease.

The immune system continues to make antibodies produced by the body to fight off the Lyme bacteria for months or years after the infection is gone. Once a person's blood tests positive, their blood may continue to test positive for months to years as the immune system remembers the infection even though the bacteria are no longer viable or present (CDC 2017d). This means that due to antibody persistence, a single serologic test cannot distinguish between active and past infection, and it cannot measure treatment response as antibody detection is expected even after completing treatment.

Additionally, you can get Lyme disease more than once. Unfortunately in the case of bacterial infections, antibodies don't prevent someone from getting the same disease again. Previous Lyme disease infection, even if successfully treated, does not prevent someone from getting Lyme disease



As with many diseases, there is no test that can "prove" a person is cured of Lyme disease.

(CDC, 2017d)

again. Reinfection of Lyme disease from repeated tick bites is well-recognized (Nadelman and Wormser, 2007).

Testing of Ticks

Although some commercial groups offer testing, in general, testing ticks is not recommended because (CDC 2017d):

- Laboratories that conduct tick testing are not required to have the high standards of quality control used by clinical diagnostic laboratories. Results of tick testing should not be used for treatment decisions.
- A tick positive for the Lyme bacteria does not necessarily mean that you have been infected.
- Negative results can lead to false assurance. A person may have been unknowingly bitten by a different tick that was infected.
- If a person is infected, symptoms may develop before results of the tick test are available and appropriate treatment should not be delayed waiting for tick testing results.

Treatment

Patients treated with antibiotics in the early stages of the infection usually recover rapidly and completely.

It is not uncommon for patients treated for Lyme disease with a recommended 2 to 4 week course of antibiotics to have lingering symptoms at the time they finish treatment. In a small percentage of cases, these symptoms can last for more than 6 months. These symptoms cannot be cured by taking antibiotics for a longer period of time, but they generally improve on their own, over time (CDC, 2017d). According to peer-reviewed studies, these lingering symptoms may be due to persisting inflammatory responses, by genetically predisposed individuals, to bacterial debris left in the body after the infection is cleared as well as joint damage caused by the initial infection (IDSA, 2012).

Most patients who are treated in later stages of the disease commonly experience symptoms of arthritis, encephalopathy, encephalomyelitis, and peripheral neuropathy. Patients treated during late stage Lyme disease also respond well to antibiotics, however, they may have suffered long-term damage to the nervous system or joints (CDC, 2017d).

For specific appropriate treatment regimens for Lyme disease, refer to the CDC's Tickborne Diseases of the United States, Reference Manual for Healthcare Providers online at: <https://www.cdc.gov/lyme/resources/TickborneDiseases.pdf>.



Post-Treatment Lyme Disease

For more than 15 years, a scientific debate has emerged about Lyme disease and the standardized use of terminology to describe patients with well-documented Lyme disease and symptoms lasting six months or more after completion of a short-term antibiotic treatment.

One viewpoint represented by the Infectious Disease Society of America (IDSA) maintains that no reliable scientific evidence exists that supports the designation of Lyme disease as a chronic disease or actively infectious disease requiring ongoing antibiotic therapy (IDSA, 2012).

The IDSA describes Lyme disease as a rare localized illness easily diagnosed in its early stage or identified in its later stages through appropriate commercial laboratory testing, and effectively treated with a short course of antibiotics.

The IDSA guidelines recommend one-time, short-term (2-4 week) antibiotic therapy. While there may be considerable impact to the health-related quality of life among 10-20% of patients with persistent symptoms following successful treatment with a short-term antibiotic, treatment with antibiotics for 90 days or more did not improve symptoms and there is a lack of evidence of continued infection based on existing methods of detection (Klempner et al, 2001). Furthermore, long-term antibiotic or alternative treatments for Lyme disease have been associated with serious complications (CDC, 2017c).

The views expressed by the Centers for Disease Control and Prevention (CDC) align with the IDSA. The NYSDOH and Madison County refer to and follow CDC testing and treatment guidelines.



The CDC has estimated that approximately 10-20% of individuals may experience lingering post-treatment Lyme disease symptoms that persist even after initial recommended 2-4 week antibiotic treatment of Lyme Disease. Symptoms that continue 6 months or longer after treatment have been termed “Post-Treatment Lyme Disease Syndrome” by the CDC (CDC, 2017c.) Similar complications and “auto-immune” responses are known to occur following other infections, causing lingering symptoms from residual damage to tissues and the immune system that occurred during the infection and not due to continued infection.

The second viewpoint is represented by the Lyme and Associated Diseases Society (ILADS) which argues that commercial lab testing for Lyme often yields inaccurate results so the disease is not recognized and persists in a large number of patients, requiring long-term antibiotic therapy to eradicate persistent or ongoing chronic infection.

ILADS provides a different set of guidelines calling for four weeks or more of antibiotic treatment and possible additional antibiotic retreatment.

Additionally some doctors, commonly aligned with the ILADS, refer to themselves as a “Lyme Literate Medical Doctors (LLMD)” or doctors well versed in Lyme and chronic Lyme disease. However, the title of LLMD is self-assigned, and no official degree or certification was discovered during the writing of this profile. The term

“Chronic Lyme disease” remains a poorly defined term that describes the attribution of various atypical syndromes to protracted Lyme disease infection (Lantos, 2015). While the term is sometimes used to describe illness in patients with Lyme disease, in many occasions it has been used to describe symptoms of illness in people who have no evidence of a current or past infection with *B. burgdorferi* (Marques, 2008). Because of the confusion in how the term Chronic Lyme disease is used and interpreted, experts in this field, including the CDC, do not support its use (Feder et al., 2007).

ILADS and The Infectious Diseases Society of America (IDSA) guidelines differ substantially, revealing the wide variation in diagnosis and treatment.

These differences in viewpoints and use of terminology, can impact the healthcare patients receive. The use of the self-assigned “LLMD” title has become more common and a 2011 study by Johnson et al found that overall, patients diagnosed with other supporting lab tests outside of the CDC recommended testing, were significantly more likely to see a greater number of physicians (4-10) prior to getting a diagnosis, than patients diagnosed by CDC criteria. This can result in additional medical visits, higher medical costs for patients.

Healthcare Costs, Utilization, and Care

Lyme disease patients may experience long delays in getting an initial diagnosis and appropriate treatment for the best health outcome. When left untreated, early Lyme disease may lead to neurological and rheumatic manifestations weeks or months later and treatment applied at late stage of illness may be less effective. A 2007 study by Cameron found

that treatment delay for Lyme disease averaged 1.8 years. This underscores the need for earlier recognition of infection as effective treatment after a delayed Lyme disease diagnosis is less successful and more costly.

Lyme disease diagnosis is associated with 87% more outpatient visits a year.
(Adrion et al, 2015)

A cost-of-illness study by Zhang et al. in 2006, found that the mean annual cost of clinically defined early stage Lyme disease was \$1,310 per patient, whereas at the clinically defined late stage the mean total cost per patient rose to \$16,199 in year 2000 dollars (Zhang et al.). Additionally, the loss of productivity such as lost work time, may make up over half of the costs associated with late Lyme disease (Zhang et al.).

Of those who applied for new health insurance following a Lyme disease diagnosis, 39.9% were denied coverage due to the diagnosis (Johnson et al., 2011). The denial of coverage for a pre-existing Lyme disease diagnosis may lead to deficient care and further delay appropriate treatment leading to disability and in turn the loss of both job (19%) and loss of insurance (Johnson et al, 2011).





Photo Credit: New York State Department of Health

According to a 2015 study by Adrion et al., of medical claim data, Lyme disease is associated with \$2,968 higher total healthcare costs and 87% more outpatient visits over a 12-month period than those with no Lyme Disease exposure. Among those with Lyme disease, having a post-treatment Lyme disease syndrome-related (PTLDS) diagnosis was associated with \$3,798 higher total health care costs and 66% more outpatient visits over a 12-month period compared to those without a PTLDS related diagnosis. Mean total costs per patient with Lyme disease were almost two times higher than patients with no Lyme diagnosis, and adjusted total costs were \$2,968 greater (Adrion et al, 2015). This is higher than the \$464-\$1,609 mean costs of treating early state Lyme disease reported by Zhang et al. in 2006, and may show the importance of accounting for costs associated with PTLDS. Additional laboratory costs may be attributed to further diagnostic testing by healthcare providers attempting to understand PTLDS symptoms experienced.

The cost of Lyme disease for patients and the nation may be exacerbated by several factors, including delayed diagnosis, less effective treatment, loss of productivity, debilitating illness, the inability to get new insurance with

Lyme disease as a pre-existing condition, and the denial of disability benefits to those unable to work (Johnson, 2011).

According to a 2011 study of 2,242 participants, by Johnson et al., nearly half of respondents reported traveling over 50 miles for treatment. It may be inferred that patients traveling longer distances for care have higher travel costs and lost work productivity.

Assuming Lyme Disease rate estimates of 240,000-444,000 cases per year in the United States and \$2,968 greater annual health care costs for those diagnosed with Lyme disease, the total direct medical costs attributed to Lyme disease and PTLDS could be between \$712 million to \$1.3 billion dollars each year (Albion, 2015). Lyme disease can be costly, and the financial burden and impact of delayed diagnosis and treatment locally has not been explored.

Tick Surveillance

Researchers from the New York State Department of Health (NYSDOH) collect and test blacklegged ticks in Madison County, and in several other counties each year. A handful of

locations in surveillance counties are selected to monitor for Lyme disease and four other tick-borne pathogens.

The NYSDOH collects ticks from publically accessible parks or trails, and the selected locations may change from year to year.

In the fall of 2015, NYSDOH field staff collected ticks from three locations in Madison County: the Towns of Eaton, Brookfield, and Hamilton. In all locations, only a few ticks (<9) were collected after several hours. In the Town of Hamilton, 9 ticks were collected-with three testing positive for the Lyme bacteria.

In the fall of 2016, field staff collected ticks in three towns: Lincoln, DeRuyter, and Hamilton (3 locations). In the Town of Lincoln, 12 of 29 adult blacklegged ticks collected were positive for Lyme bacteria. Across all three locations in Hamilton a

total of 1 of 6 ticks tested positive for the Lyme bacteria.

There are several limitations to the current tick surveillance activities conducted. The surveillance activities conducted by the NYSDOH annually only provide information about tick infection at a precise location on a publically accessible site, at one particular point in time. The surveillance data cannot be used to broadly predict disease risk for a larger area, such as for the county or the town. The percent of ticks positive for a specific pathogen is only part of the risk equation for tick borne diseases. The likelihood of encountering a tick also plays an important role, and this likelihood varies with time and location, within both the county and the state. A more robust set of tick surveillance activities would need to be implemented to better understand tick density and infection rates across the county.

Figure 9:
Potential Regional Range of the Blacklegged (Deer) Tick (CDC, 2017a)



Geographic Spread of Ticks and Lyme Disease

Figure 9 shows the potential range estimated by the CDC of the blacklegged tick. What is important to note is that although the presence of the tick may extend as far south as Florida and part of Texas, the mere presence of this tick may not accurately represent risk of Lyme disease in all areas of the U.S. Most cases of Lyme disease in people occur in the northeast quarter of the U.S., shown in Figure 10.

While climate variability and climate change both alter the transmission of vector-borne diseases, they will likely interact with many other factors, including how pathogens adapt and change, the availability of hosts, changing ecosystems and land use, demographics, human behavior, and adaptive capacity. These complex interactions make it difficult to predict the effects of climate change on vector-borne diseases (Gamble et al., 2016).

Risk for encounters with infected ticks, even in high-incidence locations is influenced by human behavior and landscape characteristics that impact the number of ticks and composition of small mammals.

Ticks live on a variety of animals including deer, rodents, birds, and other host animals. Deer do not harbor the bacteria that causes Lyme disease, but certain other hosts such as white-footed mice do, and ticks pick up the bacteria by feeding on these infected hosts.

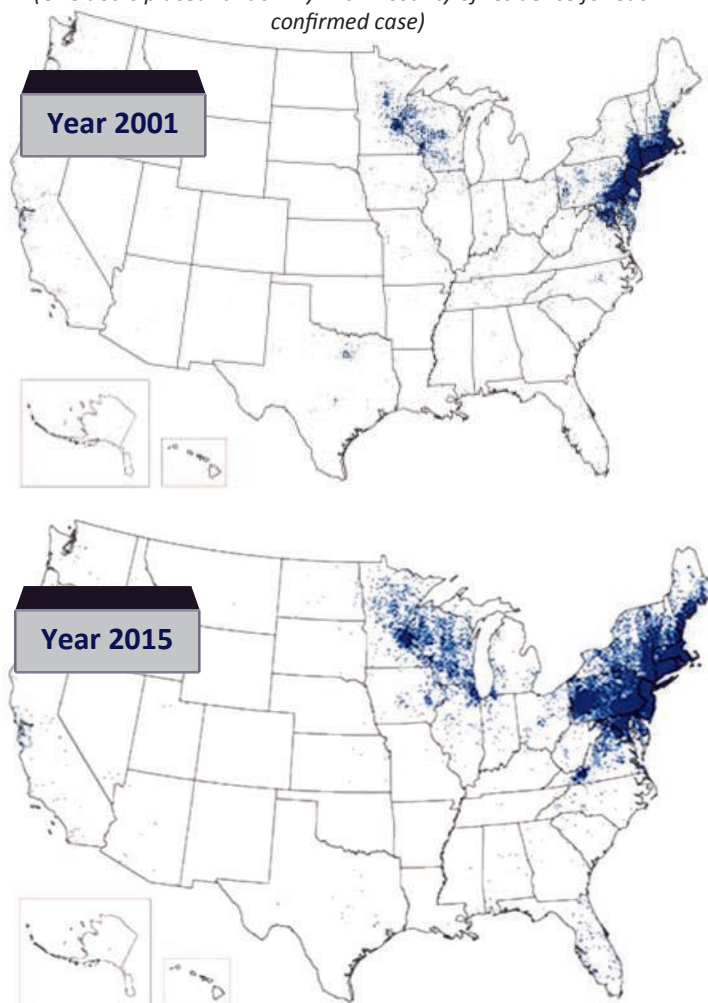
The expansion of areas with high rates of infected ticks may occur when environmental conditions change to favor tick survival or when infected ticks are dispersed by birds and deer to other places where climate and other needed components already exist to support ongoing transmission (Kugeler, 2015).

Climate is just one of many important factors that influence the transmission, distribution, and incidence of Lyme disease. Studies provide

evidence that climate change has contributed to the expanded range of ticks (Beard et al., 2016), increasing the potential risk of Lyme disease. The life cycle and prevalence of blacklegged ticks are strongly influenced by temperature (above 45°F) and humidity (at least 85-percent) (Beard et al., 2016 and Leighton et al., 2012). Thus, warming temperatures associated with climate change are projected to increase the range of suitable tick habitat and potential spread of

Figure 10:
Reported Cases of Lyme Disease — United States
(CDC, 2016a)

(One dot is placed randomly within county of residence for each confirmed case)



Lyme disease (Beard et al., 2016). Additionally, shorter winters could extend the period when ticks are active each year, increasing the time that humans could be exposed to Lyme disease. Unlike some other vector-borne diseases, tick-borne disease patterns are generally less influenced by short-term changes in weather (weeks to months) than by longer-term climate change (EPA, n.d).

The percentage of ticks that are infected may depend on the prevalence and infection rates of white-footed mice, chipmunks and shrews, along with other small mammal hosts that are reservoirs for the bacteria that causes Lyme disease.

Other factors that affect the number of Lyme disease cases include changes in the populations of larger animal host species (particularly deer), sought out by adult ticks, which may also affect tick population size.

Human exposure to infected ticks is influenced by multiple factors, including changes in the proximity to ticks and animal hosts populations, increased awareness of Lyme disease, resulting in modified personal behaviors, such as spending less time outdoors, taking precautions against being bitten, and checking more carefully for ticks. People who work outdoors, like farmers and landscapers, may be especially at risk (Gamble et al, 2016).

Targeted Tick Control Methods

In addition to climate change, the last few decades have seen shifts in land use patterns and increased closer associations between humans and wildlife that may be increasing the risk of people coming into contact with infected ticks. A number of different methods have been studied to try and control tick populations with varying success at reducing the risk of Lyme disease.



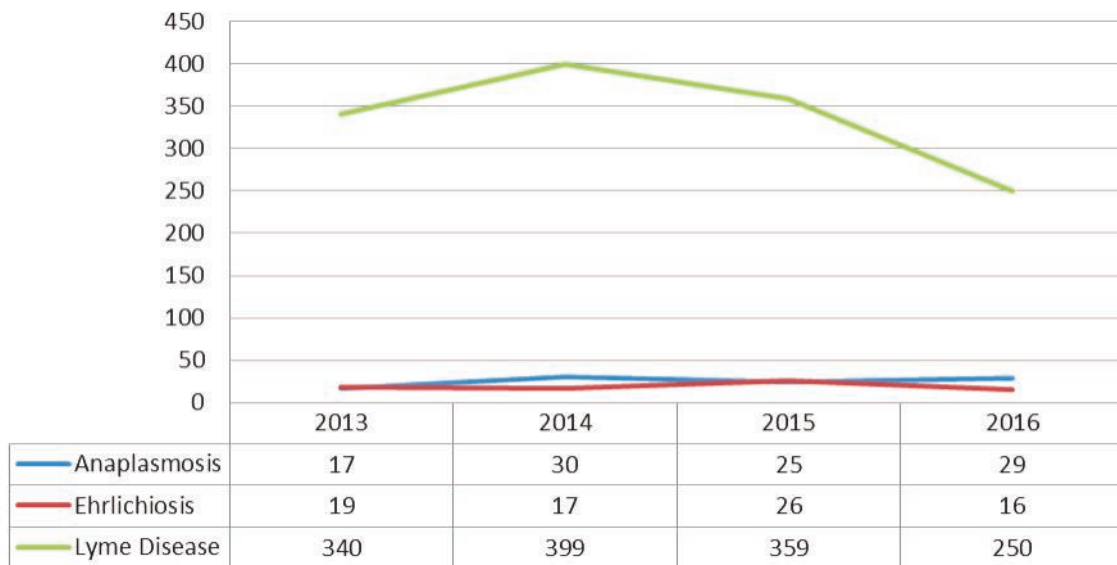
Photo Credit: Jesse Brunner, School of Biological Sciences, Washington State University

One study used tubes with cotton treated with a pesticide to kill immature ticks. Mice use the treated cotton for their nests. Ticks that come into contact with the cotton treated with permethrin are killed (Deblinger and Rimmer, 1991). Distribution of the tubes rendered nearly all mice tick free in the area and reduced the number of ticks questing on vegetation that could be encountered by a person. Reports of ticks and tick bites in the area after the intervention went from common to rare.

A second study used a tick control system of small mammal host-targeted (e.g. white-footed mouse and chipmunks) bait boxes to significantly reduce tick host infestation intensity and prevalence as well as host-seeking nymphal ticks (Schulze, 2017). Consequently, fewer ticks were able to feed on infected small mammal hosts. This method may provide a significant reduction in exposure to host-seeking ticks and reduce the use of wide-area chemical controls. More information however is needed to assess the impact of alternative reservoir hosts infected with the Lyme disease causing bacteria that ticks may seek out to feed on.

Controlled studies have also shown single springtime barrier application of acaricide to kill 68-100% of ticks. A study conducted by Hinckley et al. (2016) found that the number of questing ticks was significantly lower (63%) on acaricide-treated properties, but did not substantially

Figure 11: Veterinarians Reports of Cases of Tick-borne Disease by Year, Madison County Area (MCDOH, 2017)



reduce the risk of tick-borne disease. This finding is consistent with a growing awareness that preventing infection in people cannot be assumed based on the outcome of tick populations alone (Wilson et al, 2015).

In a literature review by the CDC, 4-Poster deer self-treatment devices were identified as moderately effective at controlling tick populations in small spatial scales with high device density under ideal conditions when used as part of a larger integrated tick management strategy (Wong et al., n.d.). The devices are not suitable for broad scale (e.g., county-wide) use and can be expensive to install and maintain long-term. While 4-Poster devices can result in a reduction in tick populations at localized spatial scales, similar to other tick control methods, this has not been directly correlated to a reduction in tick-borne illness.

Although various methods have shown success or promise to reduce tick populations, it remains unclear how tick density and infection rates correlate with human disease outcomes. Suppression of tick populations while preventing ticks feeding on host animals carrying the

bacteria that causes Lyme disease is a promising option. However, more information is needed on the social and recreational behaviors of people in high-risk areas for Lyme to determine how tick findings correlate to human disease risk (Feldman et al, 2015).

Animal Surveillance for Lyme Disease

Like humans, dogs are susceptible to Lyme disease. Dogs have been proposed as sentinels for Lyme disease risk (and potentially other tick-borne disease) as they tend to get tick bites and have a robust antibody response after infection. High seroprevalence rates of 7-18% among dogs in Lyme endemic states support dog serology as a tool for identifying areas with infected ticks (Mead, et al., 2011). In some circumstances, Mead et al (2011) found that high canine seroprevalence, greater than 5%, appears to anticipate increasing rates of human infection at the county level and may be a useful adjunct to human surveillance. Millen et al. (2013) found that dog serology data is subject to the same limitations as those of human surveillance data

Table 3: Percent of Dogs Positive for Lyme disease* (CAPC, n.d.)

	2013	2014	2015	2016	2017**
New York State	9.39 % (1 of 11)	10.52% (1 of 10)	10.33% (1 of 10)	11.01% (1 of 10)	11.15% (1 of 9)
Madison County	6.27% (1 of 16)	7.05% (1 of 15)	7.27% (1 of 14)	6.98% (1 of 15)	7.79% (1 of 13)

*The tick-borne pathogen tests are antibody-based from available tests (assays). Positive Lyme tests are indicative of either an active or a resolved infection with the pathogen. The estimated prevalence is conservative and it is believed to be much higher in the whole population. (CAPC, n.d.) **2017 data is incomplete.

and does not account for travel-related exposures, small sample sizes, and selective testing and may be best used to validate low risk in areas where the disease does not occur.

In a recent study by Watson et al., (2017), further research was called to better understand the potential function dogs may play as an early warning system for geographic expansion of emerging infection risks in humans. Ultimately the use of animal Lyme disease may assist to forecast spatial and temporal pattern risk of Lyme disease to help target public health educational campaigns and resources.

Madison County Health Department over the last several years has partnered with veterinarian practices in the area to collect data on animal diseases of potential concern to human health, including tick-borne diseases such as: Lyme disease, Anaplasmosis and Ehrlichiosis (Figure 11).

The data collected from veterinary practices demonstrates the presence of tick-borne disease locally and Lyme disease to be of primary concern presently. The data is limited, reported voluntarily, does not account for the county a pet resides in, and not all practices regularly report each month. These data estimates provide useful insight but may not provide

reliable trend data unlike data provided directly from laboratories.

Commercial laboratory data analyzed by the Companion Animal Parasite Council (Table 3), compares the number of dogs tested for Lyme to those testing positive for the disease in Madison County and New York State. The data shows the trend in the percent of dogs testing positive for Lyme disease is increasing in Madison County and New York State (Table 3). From 2013-2016, Madison County, saw a 31% increase (294 compared to 386) in dogs testing positive for Lyme disease (CAPC, n.d.). During that same time period in New York State, a 72% increase (19,985 compared to 34,432) in dogs testing positive for Lyme disease occurred (CAPC, n.d.).



Although the bacteria that causes Lyme disease is capable of infecting cats, the disease has never been seen in a cat outside of a laboratory setting, therefore cats are not an animal used to monitor Lyme disease.

State, Federal, and Community Support

In July 2016, the New York State Senate proposed a bill ([S. 5803A](#)) that would statutorily require the State Department of Health (DOH) under Public Health Law, to implement a Lyme disease and tick-borne infection awareness and prevention program within the State health care and wellness education and outreach program. Under the currently proposed bill, the program should include but not be limited to guidelines and methods for effective prevention, including the safe use of recommended insect repellents, the best practices for tick removal, recommendations for reducing exposure to ticks and what to do after a tick is removed. The *New York State Senate's Taskforce on Lyme and Tick-borne disease* website (<https://www.nysenate.gov/legislation/bills/2015/S5803/amendment/A>) listed this bill as having been passed by the New York State Senate and Assembly, but was not yet signed by the Governor into law at the time of the writing of this profile.

In December 2016, the 21 Century Cures Act was enacted into Federal law with a primary goal of promoting the development and expediting the approval of new drugs and devices and includes provisions for Lyme and Tick-borne diseases and the establishment of a federal workgroup to identify gaps in federal activities and research, and makes recommendations to the U.S. Secretary of Health and Human Services regarding how to improve the federal response to address tick-borne disease prevention, diagnosis, and treatment. The Working Group will submit and publish a report to Congress

every two years.

In August 2017, the New York State Department of Health launched a multi-faceted initiative to safeguard New Yorkers from tick-borne diseases with expanded tick surveillance and an aggressive awareness and outreach campaign in collaboration with the Department of Environmental Conservation.

In the January 2018 New York State of the State address by Governor Cuomo announced the launch of an aggressive initiative to reduce the incidence of Lyme Disease and other tick-borne illnesses in New York State, by controlling tick populations on public lands, advancing research on diagnostics and treatment, and further increasing public awareness.

- First, the Governor will direct the Departments of Health and Environmental Conservation, and the Office of Parks, Recreation and Historic Preservation to launch a tick reduction strategy targeting priority counties and public lands with the highest risk of tick exposure and Lyme disease. Tick control methods will include strategic application of ecofriendly tick control treatments to high traffic trails and facilities, as well the expanded use of 4-poster tickicide stations to treat deer and traps to treat rodents.
- Second, the Governor will direct the Commissioner of Health to establish a new working group on Lyme and other tick-borne diseases to review current strategies and improve the prevention, diagnosis and treatment of tick-borne diseases in New York State.
- Third, the Department of Health will continue its robust public outreach campaigns and also convene a tick-borne disease summit to make recommendations for future policy actions.



In addition to political support, a local community Lyme disease support group was established in 2011 and meets monthly to share information, listen and offer encouragement to others in the area. Members of local trail groups in Madison County have also received signs from Madison County Health Department and have posted the signs in areas visible to hikers to alert them to check for ticks and take steps to prevent tick bites.

Goal, Strategies and Prevention of Lyme Disease

As Lyme disease continues to become more common, education on bite prevention measures, proper tick removal, recognizing and reporting early signs and symptoms of illness, controlling tick populations, and using landscaping and habitat management techniques become important steps to reduce the risk of contracting Lyme disease locally. Strategies to reduce Lyme disease should include:

- Individuals who engage in high-risk leisure activities or occupations, especially during nymphal tick feeding season, in areas heavily infested with ticks carrying the bacteria that causes Lyme disease, are at greatest risk of infection and should be a priority for educational campaigns and interventions.

- Early diagnosis and initiation of therapy to ensure the best treatment outcome possible.
- Enhanced human and animal surveillance data to help understand and monitor disease locally now and into the future.
- Clearing or avoiding tick habitats, implementing multiple tick- and host-targeted control methods, and by using personal protection measures.
- Research beyond the county level to identify and understand relationships between tick density and tick infection levels and the relationship of tick density and animal host populations.

Future reductions in the rates of Lyme disease will require strong partnerships across multiple disciplines and organizations at the local, state, and national levels targeting these key areas. The plan of action for Madison County includes strategies to improve surveillance, integrated tick control and prevention, and education (pages 25-29).

Goal: Reduce Tick-borne Disease in Madison County

Focus Area: Surveillance

People

- Increase healthcare provider reporting suspect, probable, and confirmed Lyme disease cases by 10%.
 - Establish a baseline of suspect, probable, and confirmed Lyme disease cases reported yearly by healthcare providers and laboratories.
 - *See Outreach & Education-People:* Conduct a public health detailing campaign for at least 90% of healthcare providers to improve early recognition of signs and symptoms of Lyme disease, early diagnosis, recommended testing and treatment protocols, reporting requirements, and enhanced data collection activities.
- Determine the possibility of collecting testing data from laboratories.
- Increase weekly phone calls for tick activity and active Lyme disease surveillance to 8 healthcare provider offices.
- 25% of Lyme disease cases reported to MCDOH after April 2018, will have a completed enhanced Lyme disease case investigation (CDESS) form.
 - Develop additional risk exposure questions to enhance the Lyme disease case investigation (CDESS) form.
 - Interview 10% of confirmed Lyme disease cases reported since April 2018, to identify and/or verify exposure risk factors.
- Review Lyme disease investigations to establish a baseline of cases diagnosed with early and late manifestations of Lyme disease.
- Submit a proposal to NYSDOH to expand data collection points on the CDESS form for Lyme disease.
- Establish a comprehensive integrated vector-borne disease data management system.

Animals

- Conduct a research project to improve understanding of the interactions of key animal host and reservoir species, their densities by area, and the role they play in tick abundance and rates of tick infection locally.
 - Develop a research project proposal.
- Develop and implement a sentinel dog reporting system to establish a baseline of tick-borne disease in dogs by location of residence.
- Assess six area Veterinarian practices data/medical record systems used and what data is collected on tick-borne diseases.
- Establish an internal data system(s) to capture and analyze data collected from a sentinel dog reporting system.

Focus Area: Surveillance

Environment

- Develop maps that assist in identifying areas of high tick densities.
 - GIS map the land cover type(s) preferred by ticks and/or its key hosts by Town.
 - Develop a tick density map for Madison County.

Focus Area: Control and Prevention

People

- Increase the number of residents reporting the use of repellents effective against ticks when outdoors by 5%.
 - Develop and implement a community pre-survey to establish a baseline of repellent use by residents.
 - *See Outreach and Education-People:* Conduct a campaign for at-risk demographic groups for Lyme disease to improve awareness and prevention of Lyme disease.
 - Develop and implement a community post-survey.

Animals

- Increase the number of dogs receiving a vaccine or product to kill or repel ticks by 5%.
 - Implement a pre-survey to Veterinarians to establish a baseline estimate of the number of dogs receiving vaccine or product to kill or repel ticks.
 - Implement a pre-survey to the Community to establish a baseline estimate of the number of dogs receiving vaccine or product to kill or repel ticks.
 - *See Outreach and Education-Animals:* Implement a campaign to the veterinarians to promote dogs receiving a vaccine or product to kill or repel ticks.
 - *See Outreach and Education-Animals:* Implement a campaign to the community to promote dogs receiving a vaccine or product to kill or repel ticks.
 - Implement a post-survey to Veterinarians to establish a baseline estimate of the number of dogs receiving vaccine or product to kill or repel ticks.
 - Implement a post-survey to the Community to establish a baseline estimate of the number of dogs receiving vaccine or product to kill or repel ticks.

Focus Area: Control and Prevention

Animals

- Increase community awareness of vaccine and products to kill or repel ticks by 5%.
 - Implement a pre-survey to the Community to establish a baseline estimate of the awareness of vaccine and products to kill or repel ticks.
 - *See Outreach and Education-Animals:* Implement a campaign to the community to promote awareness of vaccine and products to kill or repel ticks.
 - Implement post-survey to the Community to establish a baseline estimate of awareness of vaccine and products to kill or repel ticks.
- Increase the awareness of best practice and/or evidence-based options for deer-proofing and deer-targeted treatments to reduce or control tick populations in an area or residential property by 10%.
 - Implement a community pre-survey on the awareness of best practice and/or evidence-based options for deer-proofing and deer-targeted treatments to reduce or control tick populations.
 - *See Outreach and Education-Environment:* Develop a factsheet on the plan's identified best practices and/or evidence-based options to reduce ticks and/or tick exposures for distribution with County tax bills.
 - Implement a community post-survey on the awareness of best practice and/or evidence-based options for deer-proofing and deer-targeted treatments to reduce or control tick populations.
- Increase the awareness of best practice and/or evidence-based options for rodent-proofing and rodent-targeted treatments to reduce or control tick populations in an area or residential property by 10%.
 - Implement a community pre-survey on the awareness of best practice and/or evidence-based options for rodent-proofing and rodent-targeted treatments to reduce or control tick populations.
 - *See Outreach and Education-Environment:* Develop a factsheet on the plan's identified best practices and/or evidence-based options to reduce ticks and/or tick exposures for distribution with County tax bills.
 - Implement a community post-survey on the awareness of best practice and/or evidence-based options for rodent-proofing and rodent-targeted treatments to reduce or control tick populations.

Focus Area: Control and Prevention

Environment

- Increase the awareness of best practice and/or evidence-based options for landscape/environmental management techniques and policies to reduce ticks and/or tick exposures by 10%.
 - Implement a community pre-survey on the awareness of best practice and/or evidence-based options for landscape/environmental management techniques and policies to reduce ticks and/or tick exposures .
 - *See Outreach and Education-Environment:* Develop a factsheet on the plan's identified best practices and/or evidence-based options to reduce ticks and/or tick exposures for distribution with County tax bills.
 - Implement a community post-survey on the awareness of best practice and/or evidence-based options for landscape/environmental management techniques and policies to reduce ticks and/or tick exposures.
- Implement an integrated vector management plan for the county.
 - Establish a multidisciplinary Lyme Prevention and Control Advisory Group.

Focus Area: Outreach and Education

People

- Implement one community event promoting awareness of Lyme disease, prevention methods, and supporting tools and/or resources.
- Implement a public health detailing campaign for healthcare providers to improve early recognition of signs and symptoms of Lyme disease, early diagnosis, recommended testing and treatment protocols, and reporting requirements.
- Implement a public health detailing campaign for at least 90% of healthcare providers to improve early recognition of signs and symptoms of Lyme disease, early diagnosis, recommended testing and treatment protocols, reporting requirements, and enhanced data collection activities.
- Host or participate in one regional professional forum or conference on Lyme disease.

Focus Area: Outreach and Education

People

- Increase the number of employers with outdoor workers providing yearly tick bite prevention information, training, and/or personal protection supplies by 5%.
 - Implement a pre-assessment among six (6) employers with outdoor employees to establish a baseline of employer activities yearly to prevent Lyme disease in workers.
 - Implement a campaign for employers with outdoor workers to improve awareness and prevention of Lyme disease.
 - Implement a post-assessment among six (6) employers with outdoor employees to establish a baseline of employer activities yearly to prevent Lyme disease in workers.
- Implement a campaign for at-risk demographic groups for Lyme disease to improve awareness and prevention of Lyme disease.
- Provide a comprehensive set of webpages on Lyme disease with tools, information, resources to reduce ticks and/or tick exposures.
 - Develop a set of webpages on Lyme disease with tools, information and resources, and posters for higher risk groups for promotion in planned public health detailing campaigns.
 - Rollout additional webpage content to include the integrated tick management plan and factsheet, along with best practices and/or evidence-based options to reduce ticks and/or tick exposures.

Animals

- Implement a campaign to the community to promote awareness of vaccine and products to kill or repel ticks.
- Implement a campaign to the community to promote dogs receiving a vaccine or product to kill or repel ticks.
- Implement a campaign to the veterinarians to promote dogs receiving a vaccine or product to kill or repel ticks.

Environment

- Rollout the integrated vector management plan to the County, Towns, Villages, and residents.
 - Develop a factsheet on the plan's identified best practices and/or evidence-based options to reduce ticks and/or tick exposures for distribution with County tax bills.
 - Present the integrated vector management plan at a County, Town and/or Village Meeting.

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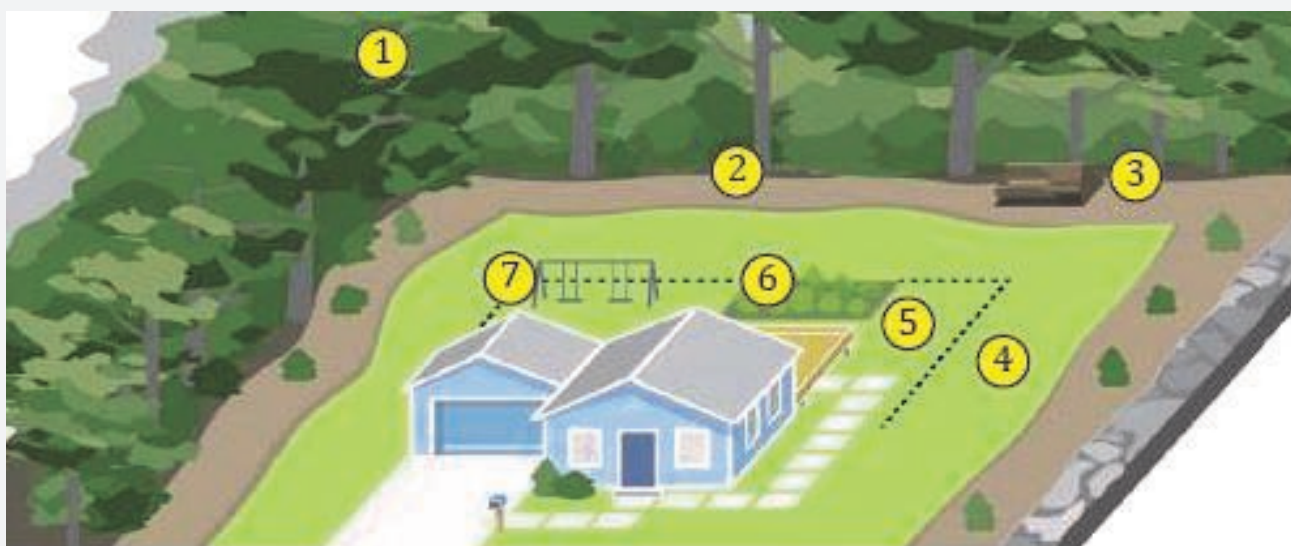
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|----------|----------------------------|---|
| 1 | Tick zone | Avoid areas with forest and brush where deer, rodents, and ticks are common. |
| 2 | Wood chip barrier | Use a 3 ft. barrier of wood chips or rock to separate the "tick zone" and rock walls from the lawn. |
| 3 | Wood pile | Keep wood piles on the wood chip barrier, away from the home. |
| 4 | Tick migration zone | Maintain a 9 ft. barrier of lawn between the wood chips and areas such as patios, gardens, and play sets. |
| 5 | Tick safe zone | Enjoy daily living activities such as gardening and outdoor play inside this perimeter. |
| 6 | Gardens | Plant deer resistant crops. If desired, an 8-ft. fence can keep deer out of the yard. |
| 7 | Play sets | Keep play sets in the "tick safe zone" in sunny areas where ticks have difficulty surviving. |

Based on a diagram by K. Stafford, Connecticut Agricultural Experiment Station

Source:

CDC. Preventing Ticks in the Yard. Retrieved from https://www.cdc.gov/lyme/prev/in_the_yard.html. Accessed March 5, 2018.



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